Challenge TB - Core Measurement Stigma

Year 2

Annual Report

October 1, 2015 – September 30, 2016

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Cover photo: Experts meeting (TB Stigma reduction meeting) in The Hague, the Netherlands, May 2016. (Credit: Monica Smits).

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1. Executive Summary

In APA2 we built upon existing platforms and USG investments to harvest available insights on TB stigma. There was a lot of raw data needing synthesis. We pinpointed the most promising and innovative tools and strategies to measure TB stigma and reduce it. We did this by partnering with TB stigma experts and stigma experts form other fields. We engaged new partners – academics to apply their skills to our problem: How to measure TB stigma efficiently, while ensuring validity and reliability.

MAJOR ACHIEVEMENTS IN YEAR 1

Challenge TB (CTB) has made significant strides in establishing a track record, a publication record, a technical network, and a niche in the arena of TB stigma measurement.

The accomplishments of the first year of the Core Stigma project include:

1. In May 2016, two meetings on TB Stigma were held in The Hague. The meetings galvanized academic, policy, and practitioner support for improved measurement and intervention on TB stigma. The meetings could leverage expertise outside the TB community to help strengthen the quality of the Social Science – avoiding some pitfalls of prior stigma measurement efforts and finding synergies with other non-TB measurement initiatives.

2. Six new studies on TB stigma measurement methods were completed and presented internationally.: two literature reviews, two DHS/SPA secondary data analyses, a scale validation in health care workers, and a scale validation in presumptive clients. Collectively, these studies represent a significant advancement in the TB measurement field—answering some basic questions that set the stage for correct measurement tools and methods in future.

These activities have resulted in new knowledge –particularly on ways to measure TB stigma, but also on the relationship between TB stigma and HIV stigma, the impact of TB stigma on health seeking behavior, the distribution of TB stigma across settings, and the correlates of stigma at individual, facility and country level. These findings are being synthesized in peer review manuscripts and will establish CTB and USAID as proactive on these issues.

2. Introduction

Stigma measurement and reduction continue to be both engaging and challenging issues for CTB and the wider TB community.

Project approach

The project aims to develop valid, feasible, and efficient methods for measurement of TB stigma at the community, patient, and health worker populations.

To meet this objective, a two-phased approach was proposed during the four-year period of the project.

Phase 1: Consultation, Consolidation (APA 2)
In phase 1 we built upon existing platforms and USG investments to harvest available insights. There was a lot of raw data needing synthesis. We pinpointed the most promising and innovative tools and strategies to measure TB stigma and reduce it. We did this by partnering with TB stigma experts (quantitative and qualitative, but primarily quantitative).

Phase 2: Investigation, Implementation (APA 3-5)
Leveraging the results of phase 1, in the second phase we will test and intervene in health care settings.

Activities supported through the project

During APA2, the following activities were completed:

a. Prevalence Survey Review

In 2015, Bill and Melinda Gates Foundation and USAID undertook an analysis of the role of prevalence surveys in TB control. KNCV's Eveline Klinkenberg provided expert support to this endeavor, having participated in multiple prevalence survey efforts. During this annual year reporting period the following milestones were reached:

- Independent assessment report was presented during the Global Task Force of impact measurement meeting in Glion (19-21 April) by USAID and served as background document

http://www.who.int/entity/tb/advisory_bodies/impact_measurement_taskforce/meetings/tf6_p07_prevalence_surveys_assessment.pdf?ua=1

- A proposal has been developed for independent oversight committees for future prevalence surveys, pilot countries are being sought, and final review process was completed. This proposal was presented to stakeholders at the WHO Prevalence survey symposium in Liverpool.

b. Assess distribution and correlates of anticipated stigma in the general population

During APA2, a DHS/SPA secondary data analysis was undertaken by KIT (sub-awardee under this project) to assess the individual and national correlates of anticipated stigma in the general population of high burden countries. It was presented in the Union conference and well received. We conclude from this study that USG investments in TB stigma reduction should prioritize Eastern Europe (e.g. Ukraine), Central Asia (e.g. Tajikistan), and selected Sub-Saharan African settings (e.g. Zimbabwe, Malawi).

c. Assess the distribution and correlates of enacted stigma in health care settings

KIT conducted a successful study of health care workers' stigmatization observations in Kenya, Namibia, and Tanzania. It was presented in the Union conference and well received. The implications of this study are:

- Stigma reduction efforts should focus upon hospitals and the complex interplay between infection control and stigma needs to be better understood and both goals – safe air and dignified care – realized.
- that investments in strengthening Human Resources for Health in stigma reduction, Human Rights, confidentiality, privacy, and patient-centered approaches probably do yield a return on investment and should not be limited to specific types of HCW.
- there is a need to trial theory-driven, evidence-based packages of anti-stigma measures in MDR and routine TB care settings to be sure that behaviors are both changed and sustained, and that any differences in behavior are palpable for patients and result in improved care seeking and/or adherence.

d. Assess robustness of existing TB stigma measures

Dr. Aaron Kipp of University of Vanderbilt conducted a global literature search to identify all TB stigma scales. The goal was to identify the TB stigma measures that have been published to date and evaluate the rigor with which they were developed and validated. The resulting search has identified 29 different TB and TB/HIV scales, most focused upon health care workers and TB patients. It was presented in the Union conference and well received. The major takeaways of the scales literature review for policy makers are:

- Few TB stigma scales meet the minimum requirements for a well-developed scale
- The Van Rie and Somma scales have been re-validated in different contexts and/or in different types of participants (e.g., TB patients, community members) and appear to function well
- There is a need for well-developed scales to measure stigma in MDR-TB patients and in health care providers.
- There is a pressing need for well-developed scales that assess the multiple dimensions of stigma – particularly structural drivers of TB stigma (i.e. caused by laws, policies), and scales which help to unpack multiple forms of exclusion.
- Brief scales (1-5 Qs) that can be easily embedded in the existing household survey mechanisms. is the most pressing policy need.

e. Systematic literature review of stigma reduction strategies (Map what works)

The systematic literature review of stigma reduction strategies by Professor Edwin Wouters of the University of Antwerp (sub-award under this project) was successfully completed. Final results of the study were presented in a symposium on Patient Support in Liverpool, and were submitted to USAID for approval prior to submission to the IJTLD. Results show that there is a dearth of reliable information on evidence-based interventions for anticipated and internalized stigma, and no evidence-based intervention for enacted stigma. http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42016036670.

f. Convene expert meeting(s)

During APA2 two experts' meetings (measurement meeting and stigma reduction meeting) were held with representation from USAID/W, WHO, Stop TB, University of Antwerp, HRSC, NLR, ICAP, Vanderbilt, AIGHD, GFATM, and CTB. The meeting generated important discussions and catalyzed several new collaborations. In addition to meeting the goals, the event also spurred several unexpected outputs (e.g. qualitative publication on low incidence settings, an NIH grant, and a successful GF grant). The Final Meeting Report is attached as an Annex 2.

g. Prepare protocol for piloting and Baseline Stigma Measurement

During APA2 it was envisioned to refine and test existing stigma measurement tools in Nigeria. A protocol was developed and refined during the expert meeting and a pre-pilot was conducted in Nigeria. However, for the following reasons: workload, pipeline, and competing priorities, it has been decided to implement this activity in Ethiopia late 2016. The goal is to have a validated tool in time for Q3 APA3.

3. Key Challenges during Implementation and Actions to Overcome Them

Despite the achievement of the project in year one, there have been challenges to implementing some activities on time and on budget.

1. The success of the core project has created a heavier than anticipated demand for tools, manuals, guidance, and TA. The urgency of assisting country programs in the short term creates pressure to compromise on quality in the interest of timeliness. It is imprudent to roll out invalidated tools but also unwise not to capitalize on the high level of interest among stakeholders.

2. The transitioning of stigma work to the APA3 country work plans has not led to widespread uptake. Many countries were interested in stigma (e.g. Bangladesh, Zimbabwe, Tajikistan) but stakeholders at the USAID mission and NTP prioritized other work areas.

3. The Nigeria CTB has declined to host the core project tool validation exercise due to workload, pipeline, and competing priorities. To address this challenge, the CTB Ethiopia team has volunteered to take up this role. We are submitting a change request to USAID/W for concurrence to shift the site to Ethiopia. If approved, Ethiopia will submit a protocol for ethical approval to validate a new HCW stigma scale in hospitals in Addis Ababa. Ethiopia has recently had two TB-stigma related deaths. MDR-TB patients needing urgent surgical intervention were refused care at several institutions or denied adequate post-operative care, leading to death. The CTB Ethiopia team and advocates plan to use these tragedies as a teachable moment to measure and intervene on stigma because of its impact on treatment outcomes. Following the measurement phase, an intervention will be developed and implemented to reduce stigma among HCW. After implementation, the intervention will be evaluated.

4. Lessons Learnt/ Next Steps

In year 2, some consolidation of the work to date is prudent. The initial work of year one should be consolidated and well disseminated in ways that favor rapid uptake.

1. The TB stigma research agenda and the IJTLD supplement are urgently needed to put TB stigma measurement into the forefront.
2. The measurement guidance is urgently requested.
3. It is vital to expand the number of partners and (CTB) consultants competent to provide TA on TB stigma measurement and TB stigma reduction. Having a critical mass of consultants who can implement and analyze TB stigma scales is strategic when the surge in stigma-measurement occurs in early 2017 (related to GFATM concept note development).
4. "Bridge Funding" has been requested to PMU and USAID to develop a stigma measurement manual (#2) and to publish a supplement to a journal (#1).

Annex 1: The Final Experts Meeting Report

Report_TB Stigma Meetings_May_2016